Biology Matters E003 - Sonya Chowdhury Transcript

[00:00:02] Steve: So I'm delighted to be joined today by Sonya Chowdhury, who is the CEO of Action for ME. Sonya is an amazing leader in the space. Um, she sits at the interface between health care, public policy, fundraising, patient advocacy, and a deep appreciation of the, um, of the research and development agenda around, uh, post infectious disorders, um, including myalgic encephalomyelitis, otherwise known as chronic fatigue syndrome, and long COVID. Um, you've been involved in several major initiatives as well as Action for ME. You're involved with the World ME Alliance, um, and also with the, uh, with the DecodeME, initiative. So thank you for coming on. It's a real pleasure to, um, to speak with you. Um, and, uh, I think probably, uh, a good place to get started for this is perhaps for you to tell, um, the listeners a little bit about the, uh, about ME and, uh, you know, what impact that the disease has on patients lives and a little bit about how prevalent it is as well. Because I think, uh, there's a distinct under appreciation of the significance of the disease.

[00:01:31] Sonya: Thank you, Steven. Thank you for your kind words too. So ME is, um, a really horrific illness. It affects over four hundred thousand people in The UK and also a much larger number, we think around one point three to one point three five million people who have ME like symptoms following an infection such as COVID. So that's quite significant numbers of people affected, let alone all the families and others that are impacted too. Many people tell us that ME steals their lives quite literally. It has horrendous symptoms which include severe persistent fatigue and exhaustion that does not improve with rest, hypersensitivities to sound, light, even touch for some people, meaning they can't be cuddled by their loved ones, gut issues, cognitive dysfunction, sleep issues, pain the list is pretty endless. The hallmark defining feature of ME is that people get a flare up of symptoms after any exertion, even a very small amount of exertion, and that can be delayed in terms of onset. It doesn't improve with rest and it can last for days, months and even longer for some people. We know that around one in four people are so severely affected, they're housebound and often bedbound. And those that are very, very severely affected need help with feeding, unable to manage independent daily living tasks And in the worst case scenarios we've seen, unfortunately, um, their lives end because they're just not able to manage nutritionally.

[00:03:28] Steve: Yeah. Yeah. I mean, you've I know you've personally been involved in in a number of, um, of very harrowing cases. How what is it like for you trying to fight for the recognition of, um, of the reality of the impact of the disease on patients? Can you talk a little bit about how, you know, recognize the disease is or isn't, and how effective, um, healthcare is at working with, um, with people who are suffering with the with the conditions?

[00:04:10] Sonya: So I'll start with the personal. I mean, you used the word harrowing, and I think, I mean, that's a very powerful word and yet it doesn't go far enough when you see the way in which people that are the most severely affected are so severely neglected beyond what you would expect. If we're not talking about an illness where there's a lack of scientific evidence base, a lack of understanding, this is serious neglect and, in some situations, abuse, and I think we have to be quite honest about that. And as somebody I'm a former child protection social worker and, um, that's where I started my career I've seen some harrowing things and the way in which some people with severe ME are treated are, you know, are up there. This is very, very serious. I have to say there are some fantastic doctors, clinicians, researchers, politicians around that are very committed to providing effective care for people, you know, professionally, politically, etc. But it doesn't go far enough. We know that there has been a stigma around the illness because the scientific base hasn't been there and that's because of a lack of funding. We know

that that has led to people being left without diagnoses, without treatments without understanding in a way that they should have. There are many illnesses where people have been left suffering and have had to wait for the science and the treatments and healthcare to catch up. We just haven't seen that quickly enough for ME. This has been going on for decades and decades and decades, and I have to say I really do believe that part of the problem has been that it affects more women than men. And we see that in other illnesses, I know you're involved in endometriosis, we see it around menopause, we see it in a whole range of other situations and that simply isn't good enough in this day and age. It really, really is not good enough.

[00:06:23] Steve: Yeah. No. Absolutely. Um, we obviously completely agree, um, on that side of things. I think there are reasons to be, um, uh, to be positive about the progress that's being made, and I'll come back to those if I may a little bit later. But, um, you mentioned your background in, um, you know, in children's social care. Um, how did you make the transition over into, um, advocacy and, you know, how what kind of skills have you brought across and experiences have you brought across that are that are useful? Because you seem to be extremely effective at, um, at advocating for patients with these diseases.

[00:07:10] Sonya: So I, um, I'm half Bangladeshi, grew up in sort of, you know, partly in Bangladeshi culture where philanthropy is huge, and, um, that sort of sense of giving back. And So I always wanted to work in the third sector, that was my ambition, um, but I also have always been moved by the injustice that people have experienced and inequity, partly through personal experience of racism but also, um, through seeing, uh, the way in which some of my friends experience disadvantage even within their own families, and that really drove me to want to become a social worker and ultimately then move into the third sector. I think the skills around, um, observation, understanding, analysis, kind of assessment, all of those things that came into play as a social worker I use today. You know, we have to work systemically in this field. I think advocacy is as much about listening as it is about talking and advocacy should rarely be about shouting. And I know that there are some in the wider community that think I and Action for ME should be shouting much louder and there are times to shout, but actually at the heart of anything that you do should be collaboration, whether that's as a social worker. You know, my job there was very much to collaborate with families, to actually try and support them to improve things, not to, um, come in hard and, um, be critical and to get alongside families but also to champion the rights, particularly of children in that situation. And that's very much what we do within Action for EMI and my whole team champion the rights of people with ME both children, adults and their families because they are facing, you know, people with ME are facing huge inequity, huge disadvantage and huge injustice and that is not acceptable. So there's a level of understanding and expertise, I guess, that, um, I've built up but a real value base of collaboration that that sits with within that.

[00:09:36] Steve: And where do you think the I mean, we've you touched earlier on, um, some of the potential reasons for there being a diagnostic gap here, um, a recognition gap of both the reality of the disease and also the severity of the disease in many cases. Why do you think it's, um, been allowed to stay to stay hidden, um, and we don't have a clinical care pathway, or we haven't until recently had a clinical care pathway that has fully recognized the reality of the disease. You touched on, you know, on the sex bias, um, female to male earlier. There are other diseases which, you know, nonetheless are better recognized than ME. Is there something specific about the disease and its symptoms that, you know, makes it difficult for clinical care to respond in in the right kind of way?

[00:10:41] Sonya: I think there are a combination of reasons aside from the ones that you've mentioned, and I think we've seen that play out with long COVID. Many people with ME cite a virus prior to, um, not getting better or to becoming ill with ME, whichever way you want to define it. And, And so we expected to see many people ill after contracting COVID and that sadly was the case. What we have seen over time after that initial shock and support for people with Long COVID is that actually things just return back to normal. Everybody goes back to day to day life and people are invisible, they're not seen, they're too ill to be out. We've just done a huge survey with over 5,000 people. Um, isolation and invisibility comes through so strongly in that data and so people aren't seen. So, when you're not seen it makes it easy to forget, it makes it easy to understand, it makes it easy to, um, maybe even malign people with an expectation you need to be back at work, what do you mean you're, you know, um, that you're in bed? That gives an image of an illness that is about being tired and we all know that that is incorrect and that it's much more than that. And often we don't talk about, you know, I avoid the phrase 'just being tired' because it's used in a very negative way against this community. I think the other thing, and this may be slightly controversial and I'm talking of fourteen years experience in this field now, I, um, I have been shocked at how certain groups of clinicians and researchers have had particular views that they have stood behind and pushed and pushed and pushed, and they've had a level of influence, That is not acceptable in a field where we're still learning and we're still learning in lots of illnesses. There should be debate, there should be challenge, and we should be able to move with the scientific evidence. I don't think that has happened in the way that it should have done in this illness. We're still seeing some of that even after the results from the DECODEME study, which were pretty conclusive, and we're seeing being reproduced and the LOCOME study that we were both involved in, etc. So I think there are a number of different variables that come into play at a broader systemic level.

[00:13:16] Steve: And, I mean, picking up on that, when we when you think about, um, the policy side of your role and the impact the socioeconomic impact of, um, you know, post infectious diseases, ME, and more recently, um, ME like symptoms caused by COVID. I we've seen, um, studies out there that showing that these have enormous impact on, uh, economic productivity, um, on contributions in the workforce, on the educational and, um, uh, career prospects of sufferers. Are you is there a, um, is there a strong argument that we can play with, um, with government in particular around, uh, you know, how what the economic impact um, could be of better therapy, um, better diagnosis, and a better clinical care pathway. Actually, returning, um, you know, a number of these patients to a healthier state, um, you know, and just making an argument from almost the opposite end, um, you know, at the at the population level rather than an individual patient level.

[00:14:43] Sonya: Absolutely. I mean, our latest calculation's around 23 and a half billion pounds a year cost to the economy using the £1,350,000 figure that I referenced earlier for people with any ME like symptoms. I think that's very conservative with a small c. I know we've got a piece of work yet to publish through the LOCOME study, the figure is slightly higher there, but that's the ME and ME like symptoms. If you start to bring in overlapping illnesses like POTS and EDS etc, then that figure will be substantially higher and that's something that the Overlapping Illness Alliance that I chair, which has, uh, a group of us came together about eighteen months, two years ago, are really committed to working on that argument. It's a very powerful argument politically and economically, but it will not go anywhere near showing the real impact because actually we know and we see just with ME that there is a disproportionate number of families subjected to unnecessary child protection procedures. That calculation isn't factored in in a system that is under extreme pressure and false allegations of fabricated induced illness and, um, or formerly known as Munchausen's, biopsy etc, the educational, um, cost of children being out of school, many of whom are not getting any form of educational support despite the legislation and best practice.

There are carers that are out of work or having to stop work because they need to care for a loved one, not even just an ill child but maybe an ill adult child or a spouse. So I think, realistically, the figures are much, much higher and they do paint a very, very powerful picture, and particularly with a Labour government that is very focused on getting people back to work and that absolutely is the right thing to do where people are well enough and able to do so. And that's, um, that is something that I, you know, we do use and I think there's more work to be done to create an even stronger, more powerful advocacy kind of message to politicians and others.

[00:17:03] Steve: Yeah. I mean, I think, you know, just to put that number in context, that's 10% of the cost of the NHS that could be saved by, you know, by returning people to health and the ability to contribute. And as you say, a relatively conservative um, estimate. I'd so they'd come back to, um, reasons to be hopeful. I'd love to get your perspective having been in this space for, um, fourteen years as you say, um, around what's changed in that time in terms of understanding of the disease, in terms of a scientific progress that's been made, and the ability perhaps to look forward um, to a time when we may be able to have effective therapies, um, that that can help, uh, these patients.

[00:18:01] Sonya: Well, I think there's lots of reasons to be hopeful. I've seen a lot of change in fourteen years. It's nowhere near enough, it's not on the level it needs to be, it's not quick enough and, you know, all of those kinds of things remain true. But there is greater understanding, you know, I see in the health service people recognizing that ME is an illness that needs to be taken seriously, that it can't just be ignored, that actually it requires people to do things differently. We can see that through the numbers of people that turn up at the Royal College of GPs conference and come to a session. One of the sessions that we were involved in people were queuing out the door and so many people signed up to be on a mailing list to get information. There is a real desire to learn more and for students coming through. We won a medical, um, MSA competition for medical students. We were inundated last year. That's fantastic, you know, so that there is a shift in people wanting to know more and understanding that they need to do better for people who have this illness. Politically, this latest government and I say cross party, I don't just mean the Labour government we are getting lots of requests to meet on a regular basis. I mean we're getting at least one or two requests a week to meet with parliamentarians, uh, and not just in Westminster, um, in the Senate in a few weeks' time. For example, we've seen parliamentarians coming forward asking us to support them in putting in bids for debates, writing speeches for them for debates, and, you know, a whole range of different things. We've got over 20 parliamentary champions for ME at the moment, and one of the arguments could be well, so what? If you read some of the social media posts particularly at the moment people are saying well, so what? You've got another Parliamentary Champion or they voted this way in a bill about, you know, something to do with welfare reform. But actually the 'so what' for me is if it was easy to solve then this problem would have been solved and things would be different right now. It's not, and we need allies and we need champions and they need to chip away. There is no big bang response to this, there is no massive golden pot of money at the end of a rainbow, you know, we're in a global crisis and the government has a really tough job to do making decisions with limited resources, limited capacity. So, actually, having a sustained present, a sustained voice for people with ME in parliament, in the public arena is so important. It creates that improved awareness, improved understanding, improved knowledge and that will lead to change. It's incremental. We're not going to achieve, you know, 'I wish we could find that nugget or that pot that says if we just do this it will create a tipping point and all these wonderful things will happen' that's not going to happen. We've got to be realistic. So what action do we take to achieve the change that is needed and recognize we've got to be persistent and dogmatic and just keep going and demonstrate real resilience in the face of a very challenging environment. And I have to say I think, you know, the media has come a long way.

We would rarely see media articles. When I first started we were writing letters to local papers just to get them talking about any. We don't target them now, actually we have relationships with The Times and with Channel four and with others that are really committed to challenging the, um, the injustice that exists for our community. I think that's a real shift. If you take parliamentarians, um, the media, the press, the health service, social care service, people starting to speak up, that voice is going to get louder and that will need to change. I recognize it's not quick enough, It's not, you know, it's not in the way that it should be, but we are getting there and we are seeing that change. You asked about research and, um, I mean obviously we've seen some great results through the DecodeME's study with, um, the genetic hits, um, levels of replication through LOCOME and identification of drugs that potentially could be repurposed, the fact that you at PrecisionLife are able to expedite some of the work, uh, in terms of, you know, helping with clinical trials. All of those things are going to improve our scientific knowledge base and will accelerate research to lead to treatments and diagnostics. We have seen money come in to sequence ME and long COVID. We've got a whole group of funders and then the £4,750,000 that has come through the government. Again, we can be really critical about that and say it's not enough, it's not going to go far enough, they should have done more, but hey, we've got to celebrate some of the wins otherwise people like me and others will just leave the field. We have to celebrate the things that we achieve and we have to use them to make us feel even more motivated to achieve more, to be more resilient, and to be more persistent.

[00:23:55] Steve: I mean, I think those are great points and, you know, I'm particularly struck by the change in understanding of the disease, um, from something that was almost unknowable and, you know, too complicated for clinicians or pharma companies, um, to get engaged with. Through the decode ME, um, study, we've collected enough data to now be able to identify a whole series of genes and mechanisms that are that are going wrong inside, um, or are leading to an increased risk of particular symptoms, um, associated with ME and, uh, and, you know, demonstrated an overlap with other post infectious conditions like long COVID, for example. Um, and I think, you know, that that feels like a fairly major step forward because it gives us a very defined, um, target to go after with many of these trials. Whereas, perhaps, one of the challenges that the field has faced because of the complexity of the disease is that there is no one drug that's going to work for absolutely everybody. And therefore, if you, you know, if you assemble a clinical trial, in the past, maybe only twenty, twenty five percent of patients have actually responded to that therapy. In many cases, it's been transformational for them, but that signal gets swamped out by the other, um, people that it doesn't work for and therefore the, you know, the drug is not approved and that area of research shuts down. It feels and, you know, I've recently been at a number of these, uh, of the research conferences. It feels like the research space is broadly energized now in a way that perhaps hasn't been true or wasn't true five years ago, ten years ago, um, around the opportunities. And we've seen a lot of clinical trials starting to spin up now with, um, you know, with designed around selecting patients because they have particular drivers of disease. And, you know, maybe trying to use this as a way of improving the odds of success and also reducing cost. Is there a how do we communicate that effectively with patients, do you think, or perhaps politicians and clinicians as well to say, hey, look, you know, we're making great strides here. There's lots of reasons to be optimistic. And, actually, the size of the prize is huge, and the amount of money that we need to get there to demonstrate success is actually relatively small.

[00:27:03] Sonya: I mean, the two bits is this sort of general kind of awareness and comms around that and I think that's happening, you know. We're saying it, you're saying it, it's being talked about at conferences, there's articles in the media, there are webinars that we do, podcasts etc that communicate that more broadly, and I think that is starting to be heard. Um, there's a difference between the ME

community and the need for hope and a feeling as though things are moving forward, but there's also that broader public base that needs to, you know, that's part of that chipping away. It's saying, 'Actually, we do need to take this seriously. Wow, there are genetic hits here, who knew and why didn't I know much about this illness before? But I think there's a broader piece around that's linked back with the advocacy question you asked earlier, which is how do you develop a very concise, almost kind of, um, to use jargon, elevator pitch that links together the problem and the cost to the economy, if we want to use the language of our current government at the moment, to the potential solution and the savings which will then help that overall picture in terms of lack of funding and capacity and demands, you know, from all kinds of different areas in terms of the budget and the treasury. And I think that is a powerful argument to be made. My view is that the government should be undertaking a cost to the economy exercise themselves so that it carries the level of validity and internal ownership that is needed and I think that is absolutely something I mean it's something we've been pushing for. I think it was, um, uh, there were many gaps in the government delivery plan and, uh, lots of things that they're not delivering on despite promising they were going to, but I do think that would have, um, that that could have been quite a significant piece of work which they could have managed internally given the level of expertise that is held across the civil service. And I, you know, I think the piece of work that we will publish through LOCOME in terms of costs of the economy, socioeconomic costing, will be powerful and it's likely to be adopted given the robustness of the work that went behind it. But actually having something that has come through the government departments itself and through the civil service will give greater ownership.

[00:29:48] Steve: Yeah. I mean, having spoken to a number of the protagonists in in that space about exactly this issue. I think you're absolutely right. I'm really impressed by the level of engagement that you're getting with parliamentarians, um, that feels like really significant progress. And I wonder if it's reflective of a broad understanding both of the impact of the disease on patients, but also on the NHS, on the economy, and the messages are very much getting out. I do wonder a little bit. I mean, we've seen, for example, Germany have a much stronger response and a much higher commitment to, um, to funding of post infectious disease research. It what would it take, do you think, what are the missing pieces in The UK to connect those dots so that, you know, we at the end of the day, most of most of the great research that's going on at the moment through DecodeME, through LOCOME, through, um, a variety of other initiatives is actually happening in The UK, and it's happening with UK patient data. We're leading the world in many ways in in the study of these diseases. What does it take us to lead the world in translation of that research into medical, you know, better therapies for patients, better clinical practice, better diagnostics. Um, what what's the missing piece, do you think?

[00:31:30] Sonya: Well, I mean, I guess you could say it's the obvious and the most easy answer, um, it's funding. So researchers need the funding to be able to undertake the research and we do not have the same level of response from the government that we've seen in Germany, The Netherlands and other places where there is designated money put out for any research. I think that's a failing for all the reasons that we've talked about. I think it's short sighted and, um, I'm not going to knock what has happened so far but it doesn't go far enough. But, of course, that's not the only issue. We know that, research into ME and also long COVID and other illnesses to some degree has not been an attractive career choice. In fact we've had very experienced researchers in this field advising people not to come into this area because of the challenges in being able to build a career, the negativity that they face within the researcher community and field, the difficulty of getting grants, etc. Now, of course, I'm sure if you had the funders and the civil servants sat here they would be saying, well, we looked at this in the government delivery plan and there is all these things that we're going to do', and my question would be, well, so what? What has shifted? How have you made the boat go faster by the actions that you've identified? What's

changed? What impact have you had? What more could you have done to create greater impact and much more quickly. And I do think there needs to be some form of restricted funding to inject into this field, to bring it up to a level playing field with other illnesses, and that is the only way that we're going to see substantial change at the speed that we need it to happen. All of these kind of smaller kind of steps will have impact and it will move things forward but it will just be far too slowly. The other thing that the government will say is, well we don't do that. Well, you know, we don't have dedicated pots of money, we don't put substantial amounts into different things well that's rubbish. We saw money go into the Dementias platform, we saw money go into the Mental Health Hub and we've seen money, you know, there have been, um, there were announcements over the last week for specific funding pots and investments, so if that can happen, why can it not happen for this group of people that are significantly neglected and are costing the economy? And I mean that's not directed at the individuals themselves, People with ME do not want to be in the situation. Who would? Nobody would for decades, um, in that situation but who would, you know, if we could if we could move people out of that when they're well enough and prevent people spiraling into a position where they are physically unable to work, then that has got to be better for everybody including the economy.

[00:34:47] Steve: Yeah. I mean, we you know, as you know, we work a lot in in ALS or motor neuron disease as well. And, you know, alongside the initiatives that you've described, um, a few years ago, 50,000,000 was found to set up the motor neuron, uh, disease research institute and to fund a series of translational studies in this space. Obviously, the ALS community has also been exceptionally good at self organizing, um, and indeed fundraising, um, including the ice bucket challenge and various other things. Is are there things that we can learn from, um, from those types of initiatives? And, you know, are there some lessons that we can we can bring across for, uh, to promote the, um, the awareness and the the level of funding for for, uh, ME?

[00:35:44] Sonya: There are lots of things to learn and believe me myself and my team spend a lot of time learning from others. And, you know, the ice bucket challenge is one of those phenomenal things that just started with an idea, somebody said we're just going to do this and it took off and the time was right, it was very creative, it was engaging, you know, I sat in the garden during lockdown with my children being covered in ice water, um, you know, all of those kinds of things, and so I think there are plenty of things that we can learn and we do speak to, as you know, we speak to other leaders in the field and other teams to understand what they're doing and what we can do better. I think if we're really honest, what really shifts things is having somebody with the power, the influence and the access that puts their weight behind it and is able to secure that funding or the policy or whatever it may be. And that's what happens, you know, if we're really truthful that's what happens. We have not yet been able to secure that within the ME and Long Covid, um, sphere and that's despite having fantastic parliamentary civil service advocates that are pushing for that change. So if anybody, if any of your listeners have the, you know, the suggestion around what could really kind of help us to move that forward and create the momentum needed, then we will happily listen to that. I do believe it will happen, but it's just not happening quick enough.

[00:37:24] Steve: I I mean, just, um, I'm gonna slightly put you on the spot here, but, um, you know, against 23 and a half billion pounds per year potential savings, what do you think it would take to actually have an organized program that can start to start to bring the first, um, effective therapies, the first effective diagnostics, um, to market. Because, you know, my sense is that once we have one of those out there, once you have something that works, it isn't an insurmountable problem anymore. And, you know, pharma companies are looking at a market with tens, hundreds of millions of patients with very little competition. Once you demonstrate that that solutions can be found, this will snowball. But what what's that quantum

of money set against the 23 and a half billion a year that would actually move the needle sufficiently far for this to be a self sustaining, um, funding issue?

[00:38:37] Sonya: Well, I I'm not in the best position to be able to answer that Steve, um, but I will if you think about it in current terms, we've got data from DecodeME and LOCOME which can already start to move things forward. We know that the NIHR have got a couple of, um, you know, looking at clinical trials and we're talking small amounts of money, you know, um, a few million, a couple of million and not even that. The piece of work that we did with a whole group of us, um, other charities, researchers, people with lived experience, who said if we had £50,000,000 we'd bring this up to the level playing field and that could create real sustainable change. If you compare that to £23,500,000,000 that's a tiny drop in the ocean. We also have to be realistic in terms of where the country is financially and economically at the moment and the pressures that are there. If the government, to Herman, has said we're going to follow what Germany has done, then I think in the next couple of years we could see major change. Pounds 10,000,000 a year would make a massive difference. There'll be many that argue it's nowhere near enough and I would agree with that, but actually it shouldn't take much to start moving that forward. I think with all of the kind of novel techniques, like the ones that you use and others are applying, then of course we get a level of acceleration in a way that we couldn't before we started to have that sort of stratification and insight that we we're starting to gain. Um, I know you and I have discussed Sequence ME and long COVID and whole genome sequencing and how long that takes versus novel techniques, we need both of those things. We need to have that genetic, what I would call basic, science that sits there and, um, for the sequence ME and long COVID we need another 15,000,000 to complete that program of work and, of course, there'll be other pieces of work that come after that. So I do think when you put all of those things together, £50,000,000 would give us a good starting point, but it has to be a starting point and not the end of the story. But we can't wait for that, you know. Even a smaller amount of money will enable your research and others' research to be able to move forward much more quickly while we do those longer, sort of, um, more in-depth studies that, um, pharma companies will need alongside the output from the novel techniques.

[00:41:25] Steve: Yeah. I wanted to switch track a little bit back to back to patients, um, and, you know, two things, uh, I have in mind. Number one is on the LECOMEI project, we brought together PrecisionLife as a UK SME. We brought together UK academia through professor Chris Ponting, University of Edinburgh, and the DecodeME study, uh, that that he and yourself were leaders on. Um, we also brought in, um, some fantastic PPIE representation. So, uh, people with lived experience of the disease both directly and as carers for people with the disease. And, um, I have to say from our perspective, that was absolutely phenomenal. Um, the level of insight, the guidance, the, um, you know, the advocacy of what was really making a difference, um, to patients and how to how to explain the science back to participants in the study was incredibly helpful. That I think is one of one of the roles that you relish the most for, um, uh, or one of the things that Action for ME does most actively. Can you talk about the importance of PPE in this context, especially in a disease that perhaps is misunderstood to the extent that that ME is.
[00:43:08] Sonya: Yep. So, I mean, and of course just going back to your kind of bringing together SME, academia, people with lived experience, and the third sector through us actually. And that's a very powerful, I think that's a very powerful kind of, um, system to create and you're absolutely right that, um, people with lived experience or patient public involvement and engagement is critical. I mean, we as an organization that is embedded in how we operate at all levels including within the border and actually about 30% of my staff team have personal lived experience of long term conditions, mostly ME. And so it has to be at the center and at the heart of everything that we do, You know, how do we know that we're creating impact without the voice of the people that we're there to serve? And organizationally, we have

been a real I think we've been a real champion of having PPE at the heart of research, and you'll know from your own experience and we know from DecodeME the science is so much better because of having people with lived experience heavily involved. We, with the DecodeME study, we could not have recruited 26, nearly 27,000 people to participate in that study without building the trust in the community. That was done not just because of us as a charity or, um, Edinburgh University but because of the involvement of people with lived experience helping us to refine what we were doing, how we were doing it, um, the communication that we had and ensuring that we challenged ourselves in a way that enabled us to do better. And I remember very early conversations with you, Steve, and the team around, well, what is PPIE and how do you do it and how you approach it to see how you as an organization have grown through that involvement. And I have to say the level of commitment, particularly from you, but from others in the team, to kind of listen and to ask and be challenged and to shift your perspective is really positive. You have to have an openness to that and for me that's what science is. It should always be about debate. You know, I say to people my experience as a mother and weaning a baby changes is it six months, three months, nine months, you know, mine was different from my mum's and my sister's and so on and we'll debate it and the evidence creates another kind of perspective. And I think the most, uh, one of the most important perspectives has to be people with lived experience of whichever disease or illness that you're or cause that you're studying or involved in. So I think there is huge value that is often missed by researchers by, um, taking what I would call a more tokenistic approach here's a leaflet, comment on it, rather than having people embedded in the design, the delivery, the communication and, um, that kind of broader sphere of work. And I know, because I see the emails that come in, that's continuing long beyond the funding has finished with LOCOME. Those debates and discussion and value that's being created from that has continued and I think that researchers within the field should demonstrate, have to demonstrate, how they're doing that in a very meaningful way that not only reflects the national standards that exist, but actually demonstrates the value that's created by operating in that way.

[00:47:08] Steve: No. I totally agree, and it's been an incredibly positive experience from our side and for the wider team. You know, one of one of the challenges for us is it's very easy to be given a dataset and to delve into the science and the technology of all of this and potentially, um, lose track of why you're doing this and what impact can be made. And I know a lot of, uh, our team have been very vocal about the benefits of, um, of the Lyft experience as part of design as well as interpretation and communication of results. I guess it sort of lends itself to a, um, to another question, which is, what do what do you think are the biggest priorities now for patients and the ME community in terms of things that they would like to see coming out of these types of research? What are the big gaps from a patient perspective particularly?

[00:48:22] Sonya: So, I mean, I would say that actually the ME community has already told us that and clinicians working in the community through a priority setting partnership, we have the top 10 plus which really is 11. We wanted the top 10 but there were two that were tied, so the top 10 plus priorities that have come through there from a research perspective and all the work that we've talked about today, the science we've talked about today, is, you know, are covered within those priorities, um, you know, and the importance of thinking about those that are severely and very, very severely affected and making sure that research is, um, kind of focused in that way and greater understanding around post exertional malaise, etc. I think there are other things, um, that we know people with ME tell us and I referred to our big survey earlier on with over 5,000 people who have not yet published results. I've seen the first cut of results. But once again, isolation comes up as one of the major, major issues. And if you think about all those horrific symptoms that people are experiencing, The challenges of being out of work, not being able to access healthcare, social care, stigma all of those kinds of things, and yet isolation remains a massive issue, which is unsurprising given that people aren't well enough to be able to engage socially, go out of

the home, you know, those kinds of things. But actually there are things that can be done. We need to challenge and, um, push for more research and more research funding and greater understanding. We need to have better access to health and social care. But actually, as a society, we've got a responsibility to, um, to help reduce isolation and to make to help reduce that invisibility and to actually see what people are experiencing, the impact of this illness, and to have better understanding. And the number of people that I've I engage with that say, 'I don't really know much about ME, but I did know somebody and they got ill and then I just didn't see them again.'

[00:50:37] Steve: Yeah.

[00:50:38] Sonya: And you think, 'so that person's become invisible to them' and I'm not blaming people, we're all busy and, you know, there's a lot of challenges in all our lives in lots of different ways, but actually when somebody becomes ill and disappears or becomes ill with cancer or other things, we see it differently. And I think as a human population, human race, we have a responsibility to be better in terms of understanding what people are experiencing and understanding that maybe somebody is so ill they're not able to come out or to have me to visit. But that doesn't stop me from just sending a message every so often, not expecting a reply but just letting them know that I'm there and I'm thinking of them. One of the most powerful services that we provide within Action for ME, that always strikes a chord with me, is our birthday card scheme for children. And I know, as a parent of a child who had ME at the age of 11, they're so isolated they're not seen you know, for a child to not get a birthday card from another child is devastating. And that's just, you know, and the messages, the impact that we hear from children who are just so joyous to get a birthday card from another child, even though they don't know them, doesn't matter. It just means they've been seen and that actually it creates a sense of belonging that's something outside of their small room or their home or the little world that they've had to exist in because ME has shrunk it so significantly. So I do think that there are many things that we can do as a society that actually can help improve lives while we're waiting for all of those other things to happen.

[00:52:36] Steve: Well, I that's phenomenal and it is, um, I know having, you know, seen, uh, other patients with who are living with more severe forms of the disease, you know, that social contact, especially with, you know, if it's with somebody who's had similar experiences, can be incredibly, um, life changing. Just, you know, the knowledge that you're not alone, not having to live through this all alone is amazing. Um, one last question, if I may. Um, I alluded to, at least, my perception that that, you know, the science around, um, around ME and long COVID has changed significantly in the last four to five years. Um, how do you know, looking forward to the next, let's say, five years. Let's take us out, you know, 2030, 2031. What are your hopes? What are your what did what makes you optimistic about where we can where we can go in the next five years or so? Where do you think realistically we're going to be by that stage?

[00:54:01] Sonya: So my hope would be that Action for ME doesn't exist, or at least doesn't exist in its current form because we're not needed in the same way. You know, any charity leader should answer that. I really fundamentally, you know, if we do our jobs well and of course we, you know, there are limitations to what we can physically do, but we should we should we should exist to not exist because that, you know, we've changed things significantly. Being realistic, in five years time that's not going to be the case. Um, but I do hope that we're starting to see, um, a raft of drugs that are available from a repurposed perspective. We know that we can expedite clinical trials, there needs to be a commitment to do that, there needs to be the funding and all of those things, but we should be seeing in five years' time drugs coming through to market, or at least that pipeline is there and it's in process. I would also hope that we'd be in a position for some form of diagnostic tool that goes beyond diagnosis of exclusion. We

know from other illnesses, whether it's MS, polio, that actually once you get that diagnostic it shifts the field significantly and, um, and it removes that kind of challenge and lack of diagnosis, under diagnosis, etc. So I would hope that we would have those two things and I do think that, being realistic, there is a level of possibility because of what we've seen over the last four or five years. I would also hope that actually we have much more openness and visibility around the impact of any long COVID, POTS those kinds of illnesses that do need to people talk about them having to come out of the shadows. They don't have to come out of the shadows, we have to take a responsibility to see what is happening behind closed doors and to take responsibility for being part of that solution. So I would hope that the general public will also help to play a part in making those things happen and ensuring that people with ME aren't invisible and making sure that those most severely affected aren't those most severely neglected, because we just don't see that in the same way in other illnesses and it's just

[00:56:35] Sonya: just not good enough.

[00:56:37] Steve: Yeah, well I think we absolutely echo, um, all of those hopes, um, you know, I think we can we're seeing great strides moving towards that. And, um, you know, I I think a collaboration I said at one of my recent talks, it's gonna take a village to, um, uh, to solve this. All of the people that we've talked about on this call have roles to play. And, um, you know, I think I I'm just incredibly impressed by the leadership of Action for ME and, um, the DecodeME project and the other initiatives that are going forward in corralling this research and bringing, um, you know, in bringing lots of interests that wouldn't necessarily have come together. Um, and just focusing on the problem and the needs of patients. So thank you very much for your leadership in in the space. Thank you for, uh, for coming on and talking about, um, ME and, uh, you know, where we've come from and, hopefully, where we're going to. Um, really appreciate your time. So thank you.

[00:57:51] Sonya: Thank you too.